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Taking Stock of the Challenges and Tensions Involved in Peer Leadership in Participatory Research about Psychosis and a Call to do Better

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Participatory research methods are not new. In fact, efforts to return some degree of control to those most directly affected by research and social interventions of various types have been around for decades, albeit better developed in some areas than others. It is nevertheless arguably fair to say that the rhetoric of participation almost always exceeds the reality. “Community advisory boards” often have no meaningful control over what decisions get made; stakeholder or community member “support staff” most frequently occupy positions with no more (and sometimes less) power than research assistants or entry level coordinators (Jones, Harrison, Aguiar, & Munro, 2014). The literature on peer involvement (particularly in countries such as the United Kingdom and Australia that have invested far more strongly in “participation”) is replete with criticisms of status quo efforts and possible reasons why such inclusion efforts have failed (McKeown, Malihi-Shoja, & Downe, 2011; Russo, 2012; Sweeney, Beresford, Faulkner, Nettle, & Rose, 2009). These include limited funding, limited access to higher education and research training, systemic discrimination and gatekeeping, and the political threat posed by more traditionally trained researchers with both academic and “lived experience” credentials and credibility. As some have argued, true change hinges on the willingness of non-peer mental health researchers to give up power and control (including strangleholds on funding) rather than padding or augmenting grant applications and promotion bids through claims of including (or having included) communities of interest.

Few who follow the politics of research in the US would disagree that—for all these reasons—we still have a long way to go in the context of promoting more substantive research leadership by those on the margins (Jones & Brown, 2012; Lived Experience Research Network, 2014). On the flip side, however—albeit very possibly as a consequence of “participatory mental health research” that is most often participatory in name only—the complexities of meaningful, multidimensional involvement are often seriously downplayed. In this column, we draw on our own experiences in an effort to draw attention to three major problematics: (a) research hierarchies; (b) the politics of identity; and (c) the implications of peer researchers with “actual” (current) disabilities.

**Research Hierarchies**

The composition of research labs and projects, a structure supported by the internal hierarchies of universities as well as extramural funders, is rarely especially egalitarian. Undergraduate research assistants, green to research, are most often the lowest staff (or volunteers) on the ladder, followed by early career graduate students, senior doctoral students, postdocs, junior faculty, and the PI of a given project or center. Academic publications reify these hierarchies, requiring a linear listing of contributions; in medical journals, the “senior investigator” or PI is typically listed last (in order to designate him/her as the “senior author”) last. Extramural funding applications (Nonfellowship) are often forbidden to adjuncts, nontenure track research staff, graduate students, and postdocs. Even the...
most dedicated “participatory researcher” is likely to find it difficult to completely buck these strictures.

In a lab the co-authors previously co-led—arguably one of the most robustly participatory psychosis research projects in the country—these implied and internalized hierarchies played out at all levels. At one point, our university forbid a community-based peer advocate (who just happened to have a PhD from an elite school) from serving as a co-PI on a “participatory” grant application; even listing her as a co-I entailed a not insignificant amount of negotiating. Other community-based “co-researchers” were forced to sign legal contracts attesting that they were under the “supervision” of university faculty. In cases that mixed undergraduate RAs both with and without lived experience of psychosis, there were tensions. Nonpeer RAs wondered why a newer and more junior RA would have immediate access to “higher level” (and more fun) tasks such as interviewing participants. Unspoken assumptions about faculty and senior graduate students’ view of the value of “lived experience” versus other research skills often seemed to create under-the-surface tensions, as RAs attempted to carve out their place in the lab (and gain the experience they felt they needed for graduate school applications).

Identity Politics

The very concept of “participatory” research typically implies the inclusion of those with direct experience of a particular set of experiences and/or membership in a particular community. (For our lab, this was psychosis/schizophrenia.) The risks of publicly identifying as a member of a highly stigmatized group, however, are far from trivial (both inside and outside the academy; cf. Horton & Tucker, 2014; Price, 2011; Weiner & Weiner, 1996). There are also personal implications that may include psychological consequences of identifying or dis-identifying with otherwise “invisible” experiences, perhaps especially when the individuals in question have conventional academic credentials (Price, 2011; Russo, 2012; Sweeney et al., 2009). Editors and reviewers of participatory research articles often request that authors identify themselves in terms of their academic credentials (Price, 2011; Russo, 2012; Sweeney et al., 2009). There are also personal implications that may include psychological consequences of identifying or dis-identifying with otherwise “invisible” experiences, perhaps especially when the individuals in question have conventional academic credentials (Price, 2011; Russo, 2012; Sweeney et al., 2009). Editors and reviewers of participatory research articles often request that authors identify themselves in terms of their academic credentials (Price, 2011; Russo, 2012; Sweeney et al., 2009). Editors and reviewers of participatory research articles often request that authors identify themselves in terms of their academic credentials (Price, 2011; Russo, 2012; Sweeney et al., 2009).

In our own experience these politics deeply affected lab relationships and raised significant questions about the claims and assumptions of “participatory” methods. At one point, for example, a key research team member with lived experience refused to publicly identify as such (or be listed on grant applications) as such. Why should she, some team members asked? Was her value more tied to what she did or could publicly represent, or to her insights? Others—including peer research team members who were already publicly disclosed—found her refusal both personally threatening and an affront to the claims of participatory research. Ultimately, most of these tensions were never resolved.

Team members also regularly struggled with doubts as to whether or not their inclusion (or relative power and authority) were truly “earned” or a deeper reflection of their skills and intellect. Even very intentional soul-searching within the team mostly could not resolve these doubts. Similarly, team members with conventional “advanced” research training, often mused as to whether or not, as trained academics, their views remained (even roughly) “representative” of nonacademic community members with psychosis.

“Actual” Disability

Perhaps one of the most enduring ironies of “higher level” peer employment is the frequency with which such employment is premised on the absence of current disability. A conventional academic focus on intellectual “strength” and logical thinking all too often leaves little room for “actual” madness (or fluctuations in mental clarity). Academic mentors are much more likely to “realistically” warn mentees that an academic career is only for those who can thrive under super-human conditions rather than press for substantive change.

In a relatively short span of time, our psychosis lab weathered not one, but at least a dozen different psychotic “breaks” or exacerbations among lab members and collaborators. While we believe that these “eruptions” of madness, perhaps more than anything else, kept our work “real” and forced us to face uncomfortable complications, they also disrupted projects and timelines and raised multiple (serious) ethical concerns. Under what circumstances could or should a more “actively psychotic” team member be included on decision making, or listed on a publication that he or she was unable to review due to symptoms? Should a given (psychosis focused) project “pause” indefinitely to await the return of a core member on medical leave, or continue without him/her in order to meet “expected” deadlines? When an RA with active psychosis submitted a flagrantly delusional (and highly inflammatory) complaint to the IRB about another team member (also with psychosis), how should the research team respond, both to the RA and to IRB representatives. (“Ignore that, he/she has a schizophrenia diagnosis and was/is clearly delusional”…or…?)

At various points, collaborators suggested seemingly “fantastic” research ideas—testing the reality of extra-terrestrial light signals, seeking to establish the function of mind control implants. What are the implications of dismissing such proposals? Or the implications of attempting to follow through on them?

DISCUSSION AND CONCLUSION

The “easy” response to many of the complexities we raise here—perhaps most obviously the third—would be to dismiss more robust peer leadership in research, particularly projects focused on psychosis/schizophrenia (the “exemplar” of madness, as Sass has described it). This is not our intended take-away. Peer leadership is, we maintain, central to any project that aims...
to dig more deeply into the complexities of both symptoms and healing. The first step—and necessary prerequisite—on the path to(ward) such projects, however, is honesty. An honest reckoning with the many tensions and structures that, in fact, make participatory research so difficult. This reckoning also suggests that it is not enough to take existing structures (and norms and expectations) and simply “plug” those with lived experience into them. We need to think differently (more creatively) and also be willing to bend our assumed rules. Perhaps most importantly, however, we also need to marshal systemic challenges to “existing” structures: to ask ourselves again what “mad” research really is or would look like, what mechanisms and protocols would actually support egalitarian, collective decision making, why and how academic (perhaps even more so than other social institutions) continues to “invisibly” exclude or marginalize those with “mental disabilities.”

REFERENCES


